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AVERTING MALPRACTICE BY INFORMATION: INFORMED CONSENT IN THE PEDIATRIC TREATMENT ENVIRONMENT

*Andrew Popper**

Some years ago, a fourteen-year old minor child, who had stepped barefoot on a piece of jagged wood, sat on the examination table in the office of a pediatrician. The parent of the minor stood at the head of the table, the pediatrician at the base, examining the wound. A needle-sized sliver of wood had entered the bottom of the left foot of the patient and had split into several pieces, causing pain and presenting the risk of infection. This approximates the dialogue that ensued:¹

Doctor: "What did you step on, a porcupine? (Laughs) Listen, the good news is that I think I can get them out fairly easily."

Patient: "Will it hurt?"

Doctor: "It won't be bad. You're a big guy. You'll barely notice it."

Parent: "What about infection?"

Doctor: "Once I get these out, we can put him on an antibiotic, but I doubt that will be needed."

Patient: "It hurts when you touch it. I think it's pretty deep."

Doctor: "You want to go to the hospital?" (Laughs)

Patient: "No."

Parent: "How long will this take?"

Doctor: "Just a few minutes." At that point a physician's assistant is called, entering the examination room a few moments later, handing

* Professor of Law, American University, Washington College of Law. I would like to thank the many students who have worked on the informed consent project including Anya Guyer, Julia Wright, Beth Uhlman, Mark Wright, and Julie Gierach.

1. The difficulty inherent in informing children about proposed medical treatment and thereafter securing consent or refusal has been addressed in isolated situations involving mature minors, abortion, sexually transmitted diseases, pregnancy, and federally funded experimentation or testing. The problems associated with doctor to minor communication have not been effectively addressed, however, in the most common interaction, basic pediatric care, and that is the problem area that prompted this Article. This research began in fall, 1995 after the events depicted in the narrative above, with a survey sent to 173 pediatricians in Montgomery County, Maryland, to determine their attitudes on informed consent and children. The full survey and all responses are on file in my office. Some of the survey results, discussed herein, convinced me that not only is a change needed, but that it would be welcomed by those doctors who spend their careers treating children.

the doctor a tray with a variety of tools apparently designed for such an event.

Doctor (to parent): "This will be easier on him if you step outside."

Parent (to patient): "Is that O.K.?"

Patient: "I guess."

Doctor: "Let's get going." In the following ten minutes, the patient experienced pain, cried (for the first time in many years), and asked the doctor to stop (request denied).

The cries were audible in the waiting room, and the parent re-entered the treatment room and, after an unsuccessful attempt to calm the patient, asked the doctor: "Can't you give him an anesthetic?"

Doctor: "We're almost done."

Patient: "Fuck! This hurts." (Parental mental note: first time that son has used the "F" word in parent's presence)

Parent (to doctor): "Really, isn't there something you can do?"

Doctor: "There! All done."

There are endless questions one might pose based on the above interaction between doctor, minor patient, and parent. Did the discourse reveal in advance the nature of the medical situation that necessitated treatment? Was the proposed treatment described in a manner understandable to the patient? Were options and alternatives discussed regarding the proposed treatment? Was information provided regarding the risks of treatment? The consequences of non-treatment? Was there an agreement, *i.e.* informed consent, on the part of the parent or the patient to undergo the proposed treatment? In the unrecorded body language of the interaction between the parties, could one infer assent or dissent? Did this interaction occur as described? Is it possible that behavior of this type continues to take place in the United States in the final moments of the twentieth century?²

DISCUSSION

While there is a dispute regarding the quality and nature of information that must be disclosed as a condition for securing "informed consent" prior to medical treatment,³ no one seriously contends that

2. This narrative is set forth to stimulate debate and is not intended to open any old wounds. Further, be assured that this was the first, and only, interaction between the patient and the pediatrician. Naturally, there is no transcript to guarantee the accuracy of each word. *Uninformed* consent could have been inferred based on the interaction between the parent and the doctor. Finally, there was no litigation after the interaction occurred.

3. *Arato v. Avedon*, 858 P.2d 598, 606 (Cal. 1993) (finding it to be "unwise to require *as a matter of law* that a particular species of information be disclosed," although the facts begged for

medical care should be provided without first explaining the nature of the treatment and the accompanying risks, at least for adult patients.⁴ Those who are eighteen years and older are entitled to such information so that a judgment can be made whether to grant permission to a health care provider to go forward with treatment.⁵ In the absence of such information, outside of well-documented exceptions,⁶ medical treatment may constitute not only medical malpractice, but also an intentional tort.⁷ Thus, it does not take a great leap in logic to conclude that the right to be informed about the nature of medical treat-

a ruling regarding content of informed consent); see *Fain v. Smith*, 479 So. 2d 1150, 1152 (Ala. 1985) (finding that all material risks should be disclosed to the patient); *Leyson v. Steuermann*, 705 P.2d 37, 47 (Haw. Ct. App. 1985) (holding that there is a duty to disclose "potential risks and hazards of the proposed treatment"); see also Joel D. Kallich & Jon F. Merz, *The Transplant Imperative: Protecting Living Donors from the Pressure to Donate*, 20 J. CORP. L. 139, 150 (1994) ("The legal doctrine of informed consent also has not been sensitive to issues involving the numerical and descriptive content of information nor to whether the . . . information . . . assists in making decisions.") (footnote omitted). Compare *Canterbury v. Spence*, 464 F.2d 772, 790 (D.C. Cir. 1972) (permitting liability only where nondisclosure would have affected the decision of a reasonable patient), with *Scott v. Bradford*, 606 P.2d 554, 559 (Okla. 1979) (rejecting the objective standard and applying a subjective standard in determining causation).

4. *Scott*, 606 P.2d at 559 (holding there is a "basic right to know and decide"); see also *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891) ("No right is held more sacred . . . than the right of every individual to the possession and control of his own person . . ."). Treatment in the absence of informed consent violates the most basic human right of "self-determination." Elizabeth Shaver, Note, *Do Not Resuscitate: The Failure to Protect the Incompetent Patient's Right of Self-Determination*, 75 CORNELL L. REV. 218, 220 (1989). The information should include "the diagnosis . . . the contemplated procedure . . . the risks . . . the prospects of success . . . the prognosis if the procedure is not performed; and . . . alternative methods of treatment." 2 DAVID W. LOUISELL & HAROLD WILLIAMS, *MEDICAL MALPRACTICE* ¶ 22.01, at 22-4 (1990).

5. W. PAGE KEETON ET AL., *PROSSER AND KEETON ON TORTS* § 32, at 190 (5th ed. 1984) ("The informed consent doctrine is based on principles of individual autonomy, . . . every person has the right to determine what shall be done to his own body.") (citation omitted). Appropriate information prior to treatment, followed by an opportunity to decide on the course of care is among the "most fundamental and basic rights of free people." Lisa Anne Hawkins, Note, *Living-Will Statutes: A Minor Oversight*, 78 VA. L. REV. 1581, 1586 (1992) (quoting JAMES M. MORRISSEY ET AL., *CONSENT AND CONFIDENTIALITY IN THE HEALTH CARE OF CHILDREN AND ADOLESCENTS: A LEGAL GUIDE* 13 (1986)). For adults, informed consent is a basic human right. William J. Morton, *The Doctrine of Informed Consent*, 6 MED. & L.J. 117, 117 (1987).

6. See *Pauscher v. Iowa Methodist Med. Ctr.*, 408 N.W.2d 355, 360 (Iowa 1987) (listing the conventional exceptions). In *American Academy of Pediatrics v. Lungren*, 940 P.2d 797 (Cal. 1997), the California Supreme Court found unconstitutional a state statute that required parental consent prior to an abortion. *Id.* at 819. The decision was based in part on the premise that for adoptions, abortion, and treatment of sexually transmitted diseases, parental consent is not required. *Id.* at 803. In light of the privacy interests involved in these exceptions, it has been argued that the right to be the sole actor in the informed consent dialogue extends to narcotic addiction, and prenatal care or treatment during delivery. Tess Pape, *Legal and Ethical Considerations of Informed Consent*, 65 AORN J. 1122, 1124 (1997).

7. In *Schloendorff v. Society of New York Hospital*, 105 N.E. 92 (N.Y. 1914), Justice Cardozo proclaimed that surgery without proper consent constitutes the trespassory tort of assault. *Id.* at 93. Later, in *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972), the trespassory tort was classified as a battery, when treatment is provided with no consent whatsoever (as opposed to insufficient or

ment is fundamental. It is therefore worth inquiring why a right so basic in the United States legal system fades away to nothingness for most people ages seventeen and under.⁸

The United Nations Convention on the Rights of the Child ("Convention")⁹ mandates that "due weight" should be given "to the views of the child according to age and maturity."¹⁰ A seminal case in Great Britain reflects the Convention position, mandating that children sixteen and under should be included in the decision making process, subject to the treating physician determining the patient to be competent.¹¹ In practice, however, "few children are asked if they agree . . . to having a blood test, or to being given a drug, or to having an operation."¹² However, the first hurdle, recognizing the right to be informed, has at least surfaced.¹³ Further, scholarship and research on informed consent and children in Great Britain reflect a presumption that minors will be involved in the informed consent dialogue.¹⁴ Similarly, there is discourse focused on the difficulty of assessing compe-

inaccurate information in an informed consent dialogue). *Id.* at 8; see KEETON ET AL., *supra* note 5, § 9, at 39-41.

8. "The requirement that medical care be provided to a minor only with the consent of the minor's parent or guardian remains the general rule . . . throughout the United States." *Lungren*, 940 P.2d at 801.

9. G.A. Res. 44/25, U.N. GAOR, 44th Sess., Supp. No. 49, at 166, U.N. Doc. A/44/736 (1989) [hereinafter CRC]. The Convention was signed by President Clinton in 1995, six years after its adoption by the United Nations. *U.S. Finally Agrees to Sign UN Accord for Children*, CHI. TRIB., Feb. 12, 1995, § 1, at 22. However, as of summer, 1997, the United States is one of only three countries that has failed to ratify the Convention. See Sir Peter Ustinov, *Winds of Change Chill Relations at the United Nations*, EUROPEAN, June 12, 1997, at 22, available in LEXIS, World Library, Eupean File.

10. CRC, *supra* note 9, at 166.

11. *Gillick v. West Norfolk & Wisbech Area Health Auth.*, 3 All E.R. 402, 408-09 (H.L. 1985) (Lord Fraser); see also Sheila A.M. McLean, *Genetic Screening of Children: The U.K. Position*, 12 J. CONTEMP. HEALTH L. & POL'Y 113, 123-24 (1995) (discussing the *Gillick* case). However, parents have the right to override a child's determination. *Re R*, 14 All E.R. 177, 185-86 (C.A. 1991) (Lord Donaldson); see also J.A. Devereux et al., *Can Children Withhold Consent to Treatment?*, 306 BRIT. MED. J. 1459, 1461 (1993) (advising physicians to act cautiously and seek legal advice when the consent of a minor is in doubt); Ross Kessel, *In the U.K. Children Just Can't Say No*, HASTINGS CTR. REP., Mar.-Apr. 1993, at 20 (noting that in Britain it has been held that a court can override the refusal of a minor to receive treatment).

12. George Rylance, *Making Decisions with Children: A Child's Rights to Share in Health Decisions Can No Longer Be Ignored*, 312 BRIT. MED. J. 794, 794 (1996). For informed consent for children to be fully embraced, Great Britain will have to undertake "[a] reorientation of many of the country's health professionals." *Id.*

13. *Id.* It can be argued that the *Gillick* mandate is not only hollow but, at best, represents the adoption of a "mature minor" rule. See *infra* note 23.

14. For example, the Institute of Public Policy Research recently published a report recommending that children receive "clear and detailed information," giving them an opportunity to "express views" and insuring that a child has the right to either "grant or withhold consent" prior to treatment, provided that the patient is "considered to be competent by a doctor acting in good faith and subject to the supervisory role of the courts." *Id.* at 794 (citing P. Alderson & J. Mont-

tency levels, in the event children become engaged actively in the consent process.¹⁵

While questions regarding the pragmatics of communication between doctor and minor patient are being asked abroad, the dialogue in the United States is of a different character. Scholars have engaged in a valuable and prolific debate exploring the theoretical origins and limits of a minor's right to be informed, with a focus on the evolution of autonomy and differentiated capacity.¹⁶ It may be that the debate has a theoretical quality because the basic right to be informed does not exist in concrete form as yet,¹⁷ and thus the focus of the academic

gomery, *Health Care Choices: Making Decisions with Children*, LONDON: INST. FOR PUB. POL'Y RES. (1996)).

15. Rachel Bulford, *Children Have Rights Too*, 314 BRIT. MED. J. 1421, 1422 (1997).

Maturity is a gradual thing which varies from child to child and young person to young person. A 13 or 14 year old who is in full possession of his or her faculties should not be prevented from knowing about his or her condition. Seven year olds have different needs and levels of understanding. This does not mean, however, that a 7 year old should be rejected as being too young to make a decision. . . . [C]hildren and young people have the right to a say in anything which affects them and for their views to be taken seriously.

Id. "Often parents do not want their children told if they have the HIV virus. Yet how can a child or young person deal with their condition if they do not know about it? . . . When someone else decides that they may be mature enough . . . ?" *Id.*; see, e.g., George Rylance et al., *Measles and Rubella Immunization: Information and Consent in Children*, 311 BRIT. MED. J. 923 (1995) (presenting a survey of 851 questionnaires that had been sent to various children to determine, from the perspective of children, the capacity to make meaningful judgments regarding medical treatment).

16. See, e.g., Katherine Hunt Federle, *Looking Ahead: An Empowerment Perspective on the Rights of Children*, 68 TEMPLE L. REV. 1585, 1593 (1995) [hereinafter Federle, *An Empowerment Perspective*]; Katherine Hunt Federle, *On the Road to Reconceiving Rights for Children: A Postfeminist Analysis of the Capacity Principle*, 42 DEPAUL L. REV. 983, 1011-15 (1993) [hereinafter Federle, *Reconceiving Rights*]; Bruce C. Hafen & Jonathan O. Hafen, *Abandoning Children to Their Autonomy: The United Nations Convention on the Rights of the Child*, 37 HARV. INT'L L.J. 449, 455 (1996); Ira C. Lupu, *The Separation of Powers and the Protection of Children*, 61 U. CHI. L. REV. 1317, 1318 (1994); Richard E. Redding, *Children's Competence to Provide Informed Consent for Mental Health Treatment*, 50 WASH. & LEE L. REV. 695, 708-09 (1993); Symposium, *Report of the Working Group on Determining the Child's Capacity to Make Decisions*, 64 FORDHAM L. REV. 1339, 1339 (1996); Charles Robert Tremper, *Respect for the Human Dignity Of Minors: What the Constitution Requires*, 39 SYRACUSE L. REV. 1293, 1314-20 (1988); Walter Wadlington, *Medical Decision Making for and by Children: Tensions Between Parent, State, and Child*, 1994 U. ILL. L. REV. 311, 314-31; Erin A. Nealy, Comment, *Medical Decision-Making for Children: A Struggle for Autonomy*, 49 SMU L. REV. 133, 159 (1995).

17. As one author noted: "As of 1986 there appears not to have been a single reported case where a physician has been held liable for treating a minor without informed consent." Redding, *supra* note 16, at 744. Twelve years later, this assessment still holds true. In the absence of a recognition of the right to be informed, this situation is likely to continue. Further, a careful and intelligent assessment of rights theory is not of immediate utility given the age-based technical legal disability of children. "[C]urrent rights theories . . . are incoherent because they cannot account for the powerlessness of children." Federle, *An Empowerment Perspective*, *supra* note 16, at 1586.

community has been to establish undeniably the entitlement to information and decision making participation prior to treatment.¹⁸ Accordingly, the methodological discussion targeting matters such as how to inform minors of differing competence levels of proposed treatment is premature.¹⁹

The short of it is that in the United States the question of how to inform children of the nature, risks, and alternatives prior to medical treatment is not yet on center stage for public dialogue. It should be. In an environment where the potential for medical malpractice liability has become a focal point for those bent on tort limitation through tort reform,²⁰ it is troubling that this same group of tort-sensitive professionals has failed to take into account not only the basic rights dialogue involving children but also the potential liability scenario.

While the case law is not yet rich with informed consent cases involving children, it may well be just a matter of time. The exceptions to maintaining the veil of darkness are growing.²¹ Permitting minors

18. Nancy Batterman, *Under Age: A Minor's Right to Consent to Health Care*, 10 *TOURO L. REV.* 637, 676 (1994); Rhonda Cohn, *Minor's Right to Consent to Medical Care*, 31 *MED. TRIAL TECH. Q.* 286, 287, 291 (1985); Martha Minow, *Rights for the Next Generation: A Feminist Approach to Children's Rights*, 9 *HARV. WOMEN'S L.J.* 1, 3-5 (1986). A lack of informed consent violates a patient's right to "bodily integrity" and "autonomy." James Bopp, Jr. & Richard E. Coleson, *A Critique of Family Members as Proxy Decisionmakers Without Legal Limits*, 12 *ISSUES L. & MED.* 133, 135 (1996).

19. There has been a more extensive discussion regarding informed consent pertaining to testing and related treatment funded through federal grants or federally financed programs. See 21 *C.F.R.* pts. 50, 56 (1997); see generally *CHILDREN AS RESEARCH SUBJECTS: SCIENCE, ETHICS, AND LAW* 133-72 (Michael A. Grodin & Leonard H. Glantz eds., 1994) (discussing methods of legally obtaining a minor's consent for research); George J. Annas, *Questing for Grails: Duplicity, Betrayal and Self-Deception in Postmodern Medical Research*, 12 *J. CONTEMP. HEALTH L. & POL'Y* 297, 314-16 (1996) (arguing for one standard of informed consent for both research and therapy); Joel E. Bernstein, *Ethical Considerations in Human Experimentation*, 15 *J. CLINICAL PHARMACOLOGY* 579 (1975) (arguing that all participants in medical studies must give "voluntary 'educated' informed consent," but "children . . . require special protection").

20. For a discussion of the effects of medical malpractice liability on tort reform, see generally NEIL VIDMAR, *MEDICAL MALPRACTICE AND THE AMERICAN JURY: CONFRONTING THE MYTHS ABOUT JURY INCOMPETENCE, DEEP POCKETS, AND OUTRAGEOUS DAMAGE AWARDS* (1995); PAUL C. WEILER, *MEDICAL MALPRACTICE ON TRIAL* (1991); Randall R. Bovbjerg, *Legislation on Medical Malpractice: Further Developments and a Preliminary Report Card*, 22 *U.C. DAVIS L. REV.* 499, 504 (1989); Kenneth M. Coughlin, *Reforming Health Care: State and Local Actions*, *BUS. & HEALTH*, Jan. 1993, at 20, available in LEXIS, News Library, Bhlth File; Martin J. Hatlie, *Professional Liability: The Case for Federal Reform*, 263 *JAMA* 584 (1990); David Randolph Smith, *Battling a Receding Tort Frontier: Constitutional Attacks on Medical Malpractice Laws*, 38 *OKLA. L. REV.* 195 (1985); Christopher S. Kozak, Note, *A Review of Federal Medical Malpractice Tort Reform Alternatives*, 19 *SETON HALL LEGIS. J.* 599 (1995).

21. Redding, *supra* note 16, at 744 (noting that as of 1986, there was no body of case law regarding the right of minors to information and participation in decision making prior to mental health treatment, but "[s]uch cases might begin to occur" where "informed consent procedures are inadequate"); accord BARRY FURROW, *MALPRACTICE IN PSYCHOTHERAPY* 65-77 (1980)

to secure abortions without parental participation in the decision making process,²² expanding the narrow "mature minor" exception,²³ and in situations involving the most powerful of individual decisions, a "do not resuscitate" order, requiring the minors' informed consent,²⁴ all suggest a shift toward increased informational and participatory rights. These are exceptions to the general rule that minors are not entitled to participatory rights in informed consent. This is so despite the deeply held belief that informed consent is "at the heart" of the doctor/patient relationship,²⁵ a reality that does not spring suddenly into existence when a person turns eighteen years of age. However, from these exceptions, one can infer that within the United States legal system, precedent exists for the following set of perceptions: children can understand information pertaining to complex treatment,²⁶ children can make decisions regarding their very lives,²⁷ and physicians can make judgments about the capacity of children to receive and assimilate information.²⁸ Taken in conjunction with the essential premise that informed consent is "at the heart" of the doctor/patient

(sorting out the complexities of the informed consent doctrine, suggesting an ideal model for the doctrine, and comparing that doctrine to the emerging constitutional right to refuse treatment).

22. *American Academy of Pediatrics v. Lungren*, 940 P.2d 797 (Cal. 1997) (holding that a minor can undergo an abortion (assuming the minor is properly informed) without parental consent); see also *H.L. v. Matheson*, 450 U.S. 398 (1981) (upholding UTAH CODE ANN. § 76-7-305(2) (1978)) (requiring a physician to notify, if possible, the parents or guardian of a minor upon whom an abortion is to be performed).

23. For an in-depth discussion of the mature minor doctrine, see Garry S. Sigman & Carolyn O'Connor, *Exploration for Physicians of the Mature Minor Doctrine*, 119 PEDIATRICS 520 (1991). In most states, this doctrine allows a physician, who determines that a minor-patient is competent to make medical decisions, to inform the patient of the risks, benefits and alternatives to treatment and to receive the minor's consent or refusal. *Id.* at 521-22; see, e.g., *Younts v. St. Francis Hosp. & Sch. of Nursing, Inc.*, 469 P.2d 330 (Kan. 1970) (holding that surgery to restore a 17-year old girl's finger did not require her parent's consent); *Cardwell v. Bechtol*, 724 S.W.2d 739 (Tenn. 1987) (adopting the mature minor exception and noting that minors over 14 may be presumed to have the capacity to consent).

24. *Belcher v. Charleston Area Med. Ctr.*, 422 S.E.2d 827, 837-38 (W. Va. 1992). But see Jessica A. Penkower, Comment, *The Potential Right of Chronically Ill Adolescents to Refuse Life-Saving Medical Treatment—Fatal Misuse of the Mature Minor Doctrine*, 45 DEPAUL L. REV. 1165 (1996).

25. *Belcher*, 422 S.E.2d at 837.

26. See *infra* note 39 and accompanying text.

27. "Age should not impose an artificial barrier to a minor's right to self determination." Jennifer L. Rosato, *The Ultimate Test of Autonomy: Should Minors Have a Right to Make Decisions Regarding Life Sustaining Treatment?*, 49 RUTGERS L. REV. 1, 5 (1996).

28. A study of treatment disputes gives yet another indication of the existence (without implementation) of pretreatment information and consultation rights. "Competent minors in litigated medical treatment disputes have significant personal rights and interests at stake, including the right[] of informed consent . . ." Susan D. Hawkins, Note, *Protecting the Rights and Interests of Competent Minors in Litigated Medical Treatment Disputes*, 64 FORDHAM L. REV. 2075, 2110 (1996).

relationship for minors as well as adults, these factors could convert into a duty of care to inform which, when breached, would result in tort liability. It would be most unfortunate if the lack of coherent standards regarding informed consent for children produced a spate of lawsuits resulting in substantial awards against physicians and their insurance carriers when this is a problem that can be solved.

Putting aside the matter of personal liability and the fact that the international community has declared that there is a fundamental right to be informed,²⁹ there is the premise that the rate and quality of healing and recovery is higher with informed patients than with those who do not understand the nature of their treatments. To test this premise, a survey was sent to pediatrics practitioners to determine their views and attitudes regarding informed consent and children.³⁰ As to the effect of information on healing, the survey set forth this statement for consideration: "Children experience greater success with medical procedures when they participate in the discussion pertaining to their treatment implication[s]."³¹ The averaged agreement level for this statement was 8.48 out of ten, the highest in the entire survey.³²

The idea that information has therapeutic value for children is not particularly novel.³³ Allowing children greater participation in medical decisions not only leads to greater compliance with the treatment, but enhances commitment to the chosen decision.³⁴ Further, when a child has the freedom to choose a course of treatment, the decision becomes internalized, giving rise to enhanced self-motivation and more effective recovery.³⁵ Personal choice encourages self-evaluative and self-reinforcing mechanisms, such as goal-setting, which are integral to a successful treatment plan.³⁶ Allowing children to participate

29. See *supra* notes 9-15 and accompanying text.

30. See *supra* note 1. The survey presented a series of statements and gave the doctors an opportunity to indicate whether they agreed or disagreed with each statement. The response options ranged from ten (10) for complete agreement to one (1) for complete disagreement. There were 161 surveys distributed and 73 responses received. The survey was sent to physicians listed in the 1994-1995 Bell Atlantic Montgomery County, Maryland, Yellow Pages under the specialty "Pediatrics."

31. See *supra* notes 1, 30.

32. This figure is the simple average of the agreement levels to the statement. Out of the 73 respondents, 62 responded with agreement levels of 7 or more. Additional results of the survey are discussed *infra* notes 87, 89-90 and accompanying text.

33. See, e.g., Bruce J. Winick, *Competency to Consent to Treatment: The Distinction Between Assent and Objection*, 28 Hous. L. Rev. 15, 46-53 (1991) (advocating the therapeutic value of having patients informed and involved).

34. *Id.* at 47; Redding, *supra* note 16, at 708-09.

35. Winick, *supra* note 33, at 49.

36. *Id.* at 48-49.

in decision making is also a check on those situations where the best interests of the child are not necessarily paramount³⁷ in selecting between treatment options.³⁸ Granting children a voice in treatment decisions allows them to protect their own interests.³⁹

The correlation between a patient's expectations and the ultimate success of the treatment (the so-called "mind-body" connection)⁴⁰ cannot function in the absence of pretreatment information to the patient.⁴¹ Since studies have demonstrated that granting adults a sense of personal control through the power to make treatment decisions has a beneficial effect on health,⁴² it stands to reason that this same

37. The presumption that a parental decision is invariably more rational or valid than that of the minor patient is not shared by some who study in the field.

[F]amily decisions often are influenced by emotional reactions . . . this emotional closeness can actually be a dangerous component in the family decision-making process. . . . [P]arents are often too distraught to understand the medical problems and options for care. . . . [During] a general period of crisis . . . problem-solving capabilities are grossly impaired. . . . [F]amily decisions often suffer from an inability to separate interests . . . [and] there is no basis for believing that family members have the ability to accurately predict the treatment preferences of relatives.

Bopp & Coleson, *supra* note 18, at 143-44, 146, 150 (citations omitted). All too often, adults have limited understanding (and even more limited recollection) of the contents of the information that is the basis of giving informed consent in their own treatment. Alan Meisel & Loren H. Roth, *What We Do and Do Not Know About Informed Consent*, 246 JAMA 2473, 2474-75 (1981).

38. "Finally, parents do not always make the best decisions for their children. . . . In addition, the parents themselves may disagree over a proposed course of medical treatment for their child." Hawkins, *supra* note 28, at 2112-13 (citations omitted).

39. See Gary B. Melton, *Children's Consent: A Problem in Law and Social Science*, in CHILDREN'S COMPETENCE TO CONSENT 1, 14-16 (Gary B. Melton et al. eds., 1983) (discussing several studies which have proven that children as young as nine reasoned as mature as adults and had the cognitive capacity to make rational decisions at a significantly earlier age than courts currently assume); Redding, *supra* note 16, at 701-09 (giving a synopsis of literature and cases in the mental health profession where parents and professionals do not act according to the best interests of the child).

40. Henry Dreher, *Proven Mind/Body Medicine: Scientific Approaches Provide Hope for Those Suffering from Chronic Conditions*, NAT. HEALTH, May 1993, at 86; see generally ELLIOTT S. DACHER, PNI: THE NEW MIND/BODY HEALING PROGRAM (1993) (focusing on psychoneuroimmunology, a nascent field that studies the interrelationship between mental or cognitive stimulus and the corresponding response of the immune system).

41. See Zenia Cleigh, *Mind over Cancerous Matter? Even as Experts Disagree, Evidence Continues to be Gathered*, SAN DIEGO UNION-TRIB., Apr. 9, 1987, at D1, available in LEXIS, News Library, Calnews File. "A study by Stanford and UC Berkeley researchers has shown that . . . cancer patients who participated in group therapy survived twice as long as those on medical treatment alone. . . . The researchers, who had begun their study thinking it would refute popular ideas that 'positive thinking' . . . could combat cancer, were stunned by the results." Dr. Donald J. DaLessio & Robert L. Goldstein, *Before Visit to Doctor, Make a Checklist*, SAN DIEGO UNION-TRIB., March 13, 1990, at D2, available in LEXIS, News Library, Calnews File.

42. Sharon Stocker, *Shelter Your Health from Emotional Stress: How to Keep Your Immunity High in the Midst of Life's Lows*, PREVENTION, Apr. 1994, at 72, 75 (paraphrasing Dr. Candace Pert) ("Our mental and emotional states must directly impact the functioning of our immune systems, and in turn, our ability to fight disease."). Stocker refers to two studies where informa-

sense of control will have a positive effect on children's health when they are given a voice in medical decisions.⁴³ A recent experiment involving hypertensive patients concluded that the degree to which patients perceived they had participated in their treatment was positively correlated with the success of that treatment.⁴⁴ Patients with a lower perceived control over decisions regarding their health care had higher blood pressure while patients with heightened involvement in decision making had increased success levels.⁴⁵ In light of the arguments favoring providing children with information and participation in decision making, it is no surprise that there have been isolated cases where courts have taken the position that a particular minor has the right to chart his or her course of treatment.⁴⁶

Two such cases, decided more than a quarter of a century ago, demonstrate the capacity of courts to mandate the participation of minors. In *In re Green*,⁴⁷ the mother of a minor with severe curvature of the spine with accompanying paralytic scoliosis refused to consent to a blood transfusion necessary to perform a spinal fusion.⁴⁸ The minor, sixteen-year old Ricky Green, was initially excluded from the decision making process.⁴⁹ Thereafter, he complained that a transfusion would have transgressed his basic beliefs.⁵⁰ The director of the state hospital responded by filing a neglect petition seeking the appointment of himself as guardian so he could consent to the transfusions.⁵¹ After the initial decision to dismiss the neglect petition was reversed,⁵² the Supreme Court of Pennsylvania held that when the life of the minor is not immediately imperiled, the personal choices of the minor should

tion and participation produced demonstrable health benefits. *Id.* at 118. In one, melanoma patients who minimized the importance of the disease had the greatest risk of recurrence. *Id.* at 119. In a second, superior healing rates were achieved by those patients in educational programs who were fully informed about melanoma. *Id.*

43. William B. Janzen & William Love, *Involving Adolescents as Active Participants in Their Own Treatment Plans*, 41 PSYCHOL. REP. 931, 933-34 (1977).

44. Frank Kee, *Patients' Prerogatives and Perceptions of Benefit*, 312 BRIT. MED. J. 958, 960 (1996).

45. *Id.* at 959.

46. See, e.g., *In re Seiferth*, 127 N.E.2d 820 (N.Y. 1955); *In re Green*, 307 A.2d 279 (Pa. 1973); *Belcher v. Charleston Area Med. Ctr.*, 422 S.E.2d 827 (W. Va. 1992). The discussion that follows should not be read to mean that there has been a shift in the legal system that obligates health care providers to engage minors in the informed consent dialogue.

47. *In re Green*, 292 A.2d 387 (Pa. 1972), *aff'd* 307 A.2d 279 (Pa. 1973).

48. *Id.* at 388. The operation was described as having the potential of abating the risk of spinal collapse which may have made it possible for the minor to become mobile and stand up. *Id.*

49. *Id.*

50. *Id.*

51. *In re Green*, 286 A.2d 681 (Pa. Super. Ct. 1971).

52. *Id.*

be central to treatment decisions.⁵³ Rather than let the matter stand based on First Amendment or parental autonomy grounds, the court found that "it would be most anomalous to ignore Ricky in this situation when we consider the preference of an intelligent child of sufficient maturity We need not extend this litany of the rights of children any further to support the proposition that *Ricky should be heard*."⁵⁴ As a result of this decision, a competency hearing was held to determine the minor's wishes.⁵⁵ Again, there was judicial review of the hearing officer's decision⁵⁶ in which the court noted that Ricky's responses confirmed that he understood the benefits of treatment, the risks of surgery (Ricky stated that no one could assure him that the operation would "come out right"), and the consequences of non-treatment—the basic information set for informed consent.⁵⁷

A similar outcome had occurred years earlier in *In re Seiferth*,⁵⁸ where a fourteen-year old boy, born with a cleft palate, refused to allow surgery to correct the condition because of his belief in mental healing.⁵⁹ Like *Green*, legal proceedings began when the state petitioned to have the boy declared neglected and to have custody transferred to the state for the purpose of consenting to such medical treatments.⁶⁰ The trial court found the minor to be mature and intelligent, noted the absence of an emergency situation, and denied the petition.⁶¹ The case was reversed on appeal⁶² and then taken to the New York Court of Appeals, which reinstated the trial court decision.⁶³ Interestingly, the court found the *recovery process* would be affected adversely without the cooperation and involvement of the minor, holding that "less would be lost by permitting the lapse of several

53. *Green*, 292 A.2d at 392. The court first addressed the right of a parent to make decisions for a minor parent: "[W]e believe the wishes of this sixteen-year old boy should be ascertained; the ultimate question, in our view, is whether a parent's religious beliefs are paramount to the possibly adverse decision of the child." *Id.*

54. *Id.* (emphasis added). The court rationalized that since children of the same age can waive constitutional rights, bring personal injury actions, and receive life sentences there is no logical basis to ignore their perspectives and beliefs on a matter as basic as intimate and personal as medical treatment or personal religious beliefs. *Id.*

55. *In re Green*, 307 A.2d 279 (Pa. 1973).

56. *Id.* There is no recorded decision from the competency hearing, other than the outcome referenced in the Supreme Court opinion.

57. *Id.* (noting the results of the evidentiary hearing conducted in the Court of Common Pleas, Family Court Division, Juvenile Branch of Philadelphia).

58. 127 N.E.2d 820 (N.Y. 1955).

59. *Id.* at 822. As in *Green*, the basic beliefs of the minor were shared by the parent. *Id.*

60. *In re Seiferth*, 127 N.Y.S.2d 63, 63 (Child. Ct. 1954).

61. *Id.* at 65.

62. *In re Seiferth*, 137 N.Y.S.2d 35, 39 (N.Y. App. Div. 1955) (ordering the child to submit to surgery against his will).

63. *Seiferth*, 127 N.E.2d at 823.

more years, when the boy may make his own decision to submit to plastic surgery, than might be sacrificed if he were compelled to undergo it now against his sincere and frightened antagonism."⁶⁴

Media reports regarding the battle for information, participation, and autonomy evidenced in *Seiferth* and *Green* are not unusual.⁶⁵ These cases underscore the necessity for the health care community to take action to articulate the right of minors to be informed, to establish workable guidelines for that process, and to distribute that information to any treatment provider for whom informed consent is required of adult patients. It makes good sense to achieve this objective voluntarily, undertaking steps that will allow the community to adjust to the process, rather than waiting for an inevitable series of malpractice cases that will result in courts writing consent protocols.

The issue of whether children should be able to assent or dissent from medical treatment derives from the tenuous legal status of children's rights.⁶⁶ It is only in the last few decades that we have moved away from the view that children are the property of the parents, or more specifically, of the father.⁶⁷ With the end of the "children as property" period has come a series of decisions that impose adult-like responsibilities on minors in part based on the premise that minors have the cognitive capacity to behave responsibly. For example, a minor will be civilly liable for harm resulting from negligent operation of

64. *Id.* The dissent worried that this was too big a decision to be given a young boy. *Id.* at 824 (Fuld, J., dissenting). The dissent agreed it would be preferable if the boy would "accede" to the operation and, if he did, then his recovery would be improved. *Id.* But, the dissent noted, there are no assurances that he would ever acquiesce to the surgery, and it would only be more traumatic when he was older. *Id.*

65. See Kathryn D. Perkins, *Kids Asserting Rights in Health Care; Support Grows for Choice in Treatment*, S.F. EXAMINER, May 1, 1995, at B10 (reporting on a 15-year old who was forcibly removed from her home by police officers and subjected against her will to painful chemotherapy for ovarian cancer and a minor who ran away from home to avoid chemotherapy that he said was killing him); see also *Behind a Boy's Decision to Forgo Treatment*, N.Y. TIMES, June 13, 1994, at A12 (describing the case of Benny Agrelo, a teenager who refused to take anti-rejection therapy after having undergone a liver transplant because of excruciating side effects); Nancy San Martin, *Defiant Transplant Patient Dies at Home*, SUN-SENTINEL (Ft. Lauderdale), Aug. 21, 1994, at A8, available in LEXIS, News Library, Sunsen File (reporting Benny Agrelo's death shortly after he stopped taking his medication); Gail B. Slap & Martha M. Jablow, *Debating Rights of Young Patients*, N.Y. TIMES, Nov. 10, 1994, at C1 (discussing the problems that families and medical professionals face when teenagers refuse treatment).

66. See Melton, *supra* note 39, at 1-18.

67. Hawkins, *supra* note 28, at 2076; see also Gerald P. Koocher, *Different Lenses: Psycho-Legal Perspectives on Children's Rights*, 16 NOVA L. REV. 711, 712-13 (1992) (stating that children's rights were not recognized until the mid-1960s when children were officially deemed "persons" protected by the Fourteenth Amendment); Michael S. Wald, *Children's Rights: A Framework for Analysis*, 12 U.C. DAVIS L. REV. 255, 255 (1974) (noting that the idea that there is a debate about the rights of children is itself a new phenomenon).

an inherently dangerous instrumentality.⁶⁸ Further, in some instances, children are as liable as adults are when they participate in the kinds of activities in which adults engage that have an escalated probability of harm.⁶⁹ In other legal contexts, children have been held to have the capacity to understand and, if they so choose, waive Miranda rights,⁷⁰ receive a life sentence,⁷¹ and bring a personal injury suit.⁷² However, the cognitive premise for these obligations and corresponding informational rights is construed as insufficient when children are patients. Unless a child is deemed a mature minor⁷³ (an admittedly subjective assessment reserved to a limited number of bright and vocal children), is emancipated,⁷⁴ or is specifically given statutory⁷⁵ or judicial permission⁷⁶ to make medical care decisions, a child's parent or guardian has the exclusive legal capacity to consent to or refuse a child's medical treatment.⁷⁷

68. *Ewing v. Biddle*, 216 N.E.2d 863, 866-67 (Ind. Ct. App. 1966) (applying an adult standard of care to a child using a go-cart); *Davis v. Waterman*, 420 So. 2d 1063, 1063 (Miss. 1982) (applying an adult standard of care to a 13-year old operating a motor bike); *Neumann v. Shlansky*, 294 N.Y.S.2d 628, 632 (Westchester County Ct. 1968) (applying an adult standard of care to a minor playing golf); *Robinson v. Lindsay*, 598 P.2d 392, 394 (Wash. 1978) (applying an adult standard of care to a 13-year old operating a snowmobile).

69. See *Stevens v. Calumet Pub. Sch.*, 226 Mich. App. 441, 445 (Ct. App. 1997); *Farm Bureau Ins. Group v. Phillips*, 323 N.W.2d 477, 478 (Mich. Ct. App. 1982); *State v. DeFlorio*, 512 A.2d 1133, 1137 (N.H. 1986); RESTATEMENT (SECOND) OF TORTS § 283A cmt. c (1965); KEETON ET AL., *supra* note 5, § 32, at 181 & nn.65-67.

70. *Fare v. Michael C.*, 442 U.S. 707, 728 (1979) (establishing that a "totality of the circumstances" standard should be used to consider whether a minor voluntarily and knowingly waived his Miranda rights); *United States v. Saucedo-Velasquez*, 843 F.2d 832, 835 (5th Cir. 1988) (holding that even alien juveniles have the capacity to waive the right against self-incrimination).

71. For a discussion of the capacity of minors to function in the legal system without parental participation, see *Commonwealth v. Fogan*, 296 A.2d 755 (Pa. 1972); *Commonwealth v. Moses*, 287 A.2d 131 (Pa. 1971); *Theriault v. State*, 223 N.W.2d 850 (Wis. 1974).

72. See *Frye v. Frye*, 505 A.2d 826 (Md. 1986); *Falco v. Pados*, 282 A.2d 351 (Pa. 1971); *Rear-don v. Wilburn*, 272 A.2d 888 (Pa. 1971).

73. See *supra* note 23.

74. See *Redding*, *supra* note 16, at 712 ("Emancipated minor laws allow minors to give consent for certain enumerated treatments."). Generally, this "applies to children who live on their own away from home, who are married, or who have a child or who are financially self-sufficient." *Id.*

75. See, e.g., ALA. CODE § 22-8-4 (1990) ("Any minor who is 14 years of age or older, or has graduated from high school, or is married, or having been married is divorced, or is pregnant may give effective consent to any legally authorized medical, dental, health or mental health services for himself or herself, and the consent of no other person shall be necessary.").

76. See, e.g., *Younts v. St. Francis Hosp. & Sch. of Nursing, Inc.*, 469 P.2d 330 (Kan. 1970) (recognizing the mature minor exception); *Cardwell v. Bechtol*, 724 S.W.2d 739 (Tenn. 1987) (creating the mature minor exception in Tennessee); *Redding*, *supra* note 16, at 712 (noting that courts may find a child is near enough to majority and "mature" enough to make his or her own medical decision when doing so would be in the best interest of the child).

77. *American Academy of Pediatrics v. Lungren*, 940 P.2d 797, 801 (Cal. 1997).

There is a middle ground between full informed consent by a minor with unconditional veto power and complete denial of information and decision making: informed assent. The operating assumption for informed assent is that children capable of meaningful speech and discussion are competent to hear information and express an opinion.⁷⁸ The content and complexity of that speech will vary based on age and development. However, merely because children vary in their developmental capacities⁷⁹ does not mean they are any less entitled to understandable information needed to express an opinion on the plan of treatment.⁸⁰ To do so, a minor must know the diagnoses, the nature and risks of the proposed treatment, the alternatives to treatment, and the consequences of non-treatment.⁸¹ Given the expanding number and variety of exceptions regarding informed consent, the increase in controversial treatment refusals supported by the courts and public opinion,⁸² the acceptance in the international community of the right (albeit hollow in most of those countries) to be informed,⁸³ and the views in the medical community regarding the health value of information,⁸⁴ consideration of an expansive assent rule seems only prudent.

A MODEST PROPOSAL AND AN ACKNOWLEDGMENT OF ANTICIPATED CRITICISM

The survey mentioned earlier in this Article⁸⁵ revealed not just a belief in the value of information, but also a frustration. While there was broad agreement on the proposition that well-informed minor patients enjoy superior healing or recovery rates compared to those who

78. Federle, *Reconceiving Rights*, *supra* note 16, at 1011-15; Hawkins, *supra* note 28, at 2118-28; Rosato, *supra* note 27, at 21-22.

79. The variation in the capacity or competence levels of children has been used to block the implementation of informational and participatory rights of minors. See Redding, *supra* note 16, at 706-07 & n.58. "Consequently, some proponents of children's rights find themselves involved in an apparently unwinnable debate about children's competencies and their capacities for making rational choices." Federle, *An Empowerment Perspective*, *supra* note 16, at 1588 (footnote omitted). "The law of informed consent remains ineffective at resolving patient comprehension issues" Pape, *supra* note 6, at 1126.

80. Koocher, *supra* note 67, at 716.

81. See LOUISELL & WILLIAMS, *supra* note 4, ¶ 22.01, at 594.44; Committee on Bioethics, American Academy of Pediatrics, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, 95 PEDIATRICS 314, 314-15 (1995).

82. See generally Rosato, *supra* note 27 (discussing several decisions by state supreme courts and the public response to those decisions).

83. See *supra* notes 9-15 and accompanying text.

84. See *supra* notes 33-45 and accompanying text.

85. See *supra* notes 1, 30.

are uninformed,⁸⁶ pediatricians understand (but do not respect uniformly) that information relevant to treatment decisions is owed to the parent or guardian, not to the minor patient.⁸⁷ The preceding sections of this Article suggest why, as a matter of basic rights, personal liability, and effectiveness in care, information should be provided to the minor. The survey responses affirmed this hypothesis and further confirmed the premise that delivering information solely to a parent or guardian can create problems.⁸⁸ More than half of the pediatricians responding agreed with the statement that "parental anxiety or other factors . . . cause[] many parents to consent . . . without fully exploring the alternatives and risks of treatment."⁸⁹ Further, the survey responses underscored the difficulty associated with providing information to minor patients who, by virtue of age and other factors, have significantly diverse rates of comprehension and judgment.⁹⁰ This factor may be partially responsible for the unwillingness of courts and legislatures in this country to acknowledge the basic human right to be informed.⁹¹ One survey respondent was provoked to write, next to the statement on differential capacity: "This is an insoluble problem."⁹²

The difficulties associated with informing patients of proposed treatment, risks, and alternatives do not end with the burden of dealing with differential capacity. Even assuming that children were to be primary participants at the pretreatment information stage, there is

86. See *supra* notes 31-32 and accompanying text.

87. The survey stated: "I believe my primary duty to inform prior to treatment of a minor patient is owed to the parent." The agreement rate on this question was 7.70 on a 10 point scale. There were 73 responses. Sixty of the responses marked the question in the clear agreement range (7-10), but ten responded in the clear disagreement range (1-4), suggesting a conflict between the current set of legal obligations that mandates information to parents and guardians and the judgment of 15% of the pediatricians who believe that their duty is owed to their patients.

88. See Bopp & Coleson, *supra* note 18, at 133 (noting that family turmoil, lack of information, conflicting interests, emotional attachments, or lack of emotional attachments may adversely affect family members' decision making capabilities); Hawkins, *supra* note 28, at 2112-13 (stating the proposition that there are many situations where parents and guardians will make decisions adverse to the perceived best health care interest of their children due to misunderstanding, disinterest, anxiety, and family strife).

89. The averaged response rate to the question of whether parental anxiety or other factors resulted in parents consenting without information regarding "risks and alternatives" was 6.01. Out of 72 responses, 38 clearly agreed, 17 clearly disagreed.

90. The survey stated: "When it comes to children 17 years and younger, there are problems determining who is capable of understanding and reasoning, and who is not." The averaged response rate for this statement was 6.24. Forty-five out of 72 respondents generally agreed with this statement and only nine clearly disagreed.

91. See Federle, *An Empowerment Perspective*, *supra* note 16, at 1586 ("[R]ights theories . . . are incoherent.").

92. See *supra* notes 1, 30.

great disagreement about what should happen next. Should children have a right to veto proposed treatment over the objection of a parent or guardian?⁹³ Is information meaningful if it is not followed with the opportunity to exercise judgment and discretion?⁹⁴ Undoubtedly, these problems are perceived as significant, but at this time, they are hypothetical because children receive little or no information. At the outset of this century, if engineers in the United States had been required to solve all foreseeable problems associated with unsafe driving *before* automobiles were permitted to be sold, we would be the only industrialized country still reliant on the horse and buggy.

Some of the most provocative and powerful legal writing on children consists, in part, of advocacy seeking a declaration that minor patients have the right to informed consent,⁹⁵ and the corresponding right to have their decisions become the primary determinant regarding proposed treatment.⁹⁶ Countervailing arguments regarding the "insoluble problem" of differentiated capacity and the necessity of parental or guardian participation and control have kept this right limited to a tiny fraction of cases.⁹⁷ Beyond the obvious importance of parental or guardianship control, the potential for liability, the need for uniformity in dealing with large number of patients, and the challenges of adult to child communication, lies a deeper resistance to the declaration of the right—the fear that children, empowered with information and the right to be heard (dispositively), will make problematic, illogical, irrational, decisions.⁹⁸ This potent concern cannot be addressed in a meaningful manner in the absence of data to substantiate or refute the fear of poor decision making. However, unlike the example of the "unbuilt" automobile, data can be developed in advance to ascertain whether this fear—which keeps millions of children in the dark, depriving them of human rights declared fundamental—is real. Further, the "veto" dilemma (if children are informed,

93. See Redding, *supra* note 16, at 696 n.3 (noting that a veto already exists in certain situations).

94. See Rosato, *supra* note 27, at 8 (taking the position that in life and death treatment decisions, the child must have autonomy and the capacity to refuse treatment). The author asserts that this right to exercise decisional power in life-sustaining treatment cases should be recognized, "despite their legal inability to make less significant decisions for themselves." *Id.*

95. See generally Federle, *An Empowerment Perspective*, *supra* note 16 (suggesting an "empowerment rights" perspective with regards to children's rights); Federle, *Reconceiving Rights*, *supra* note 16 (discussing various theories made to either justify or deny a child the choice to make medical decisions); Tremper, *supra* note 16 (advising methods for revision of jurisprudence in order to bring children's status in society up to the universal standards of respect for human dignity); see also *supra* note 5 and accompanying text.

96. See *supra* notes 4, 5, 16, 18, 88.

97. See *supra* note 6; Federle, *An Empowerment Perspective*, *supra* note 16, at 1587-88.

98. See Melton, *supra* note 39, at 4-11.

thereafter they have absolute say regarding proposed treatment) need not be resolved in advance of developing the data.

Given the magnitude of the informed consent problem and the inherent liability risks, it seems appropriate to initiate a broad experiment designed to learn what happens when children capable of speech and communication are informed about the nature, alternatives, and risks of proposed treatment. Since the law has not yet changed, however, the ultimate treatment decision still rests with the parent or guardian. After the collection of this information, it will be possible to assess whether the fear of irrational judgment justifies the denial of a human right.

To initiate this inquiry, forms and response cards will be sent to the pediatricians in the initial survey⁹⁹ as well as to a broader population of care providers who predominantly treat minors. Further, subject to the significant constraints associated with the collection of empirical data from research subjects who are minors, patient questionnaires will be distributed and collected at a number of treatment sites. The goal is to document a substantial number of doctor/minor patient interactions and learn whether the information seemed to be understood by the minor, and whether the preference expressed by the minor patient was consistent with the judgment of the parent or guardian and, severally, consistent with the "best medical judgment" of the pediatrician.

Given the passionate beliefs in this field, it is not difficult to imagine the criticisms that will be raised. At this stage, only three will be mentioned. First, the right of children to be fully informed and active decision makers is compromised by a study that disempowers the children from the outset. Second, the respondents have an interest in limiting time-consuming interactions with minor patients and perhaps a bias as to the outcome. Third, the methodology is inconsistent with well-developed guidelines for research of this nature.

As to the first anticipated criticism, this survey presupposes that children will not be the primary decision makers in the informed consent dialogue during the term of the survey because, due to the current state of the law, they do not have this right. To acknowledge that this right does not exist at this time is, to an extent, heretical and could be (wrongfully) interpreted as advocacy contrary to the proper demands of those who have fought so long and hard for participation.¹⁰⁰ Quite obviously, the intent of the survey is not to cement in place a set

99. See *supra* notes 1, 30.

100. See *supra* notes 16-17, 95-96 and accompanying text.

of rules that obligates pediatricians to inform minors and then close the minors out of the decisional process, but rather to assess whether information can be understood by minor patients (as factored by age and differential capacity), and then assess the responses to the information put forward by the minors.

The second criticism—that pediatricians have a predisposition to minimize the dialogue of informed consent, not expand it—cannot be supported based on the results of the survey discussed in this Article.¹⁰¹ That is not to say that there is an absence of bias. At this point, however, in the absence of other available mechanisms to test the premises underlying expansion of informational rights, the survey method described earlier will be used.

Finally, there are numerous linguistic and empirical challenges with a survey of this nature from the perspective of conventional norms for data gathering. Before the survey instruments are sent out, there will be a review of the entire proposed study and those changes deemed necessary to conform to the conventions for such work will be implemented.

Collection and analysis of data of the type described above will take several years. In the interim, it is possible that minors will achieve full informational and participatory rights through legislation or judicial decisions—perhaps based on precedent setting and monumental mal-practice awards. Past experience, however, indicates that these changes will not occur without a struggle against the fear, distrust, misinformation, and prejudices that have, thus far, kept children in the dark. It is time to change a destructive practice that has continued, unabated, for too long. Hopefully, the data generated by the survey just described will be of use in achieving that goal.

101. *See supra* notes 1, 30.